Pump Up the Volume

A Report
from the
Mental Health
Advocate of BC

Inside...

Foreword

The Ombudsman called her 1994 Review of Administrative Fairness at Riverview Hospital "*Listening,*" to reflect the fact that a keystone of administrative fairness is the right to be heard.

This is six years later, and although people with mental illness have gained the right to be heard, the response from the system continues to be troubling.

When my children ask me to "pump up the volume" on the CD player, they are telling me they like the music and they want more of it.

People with mental illness in this province and the people who care about them have told me they want more from the people of BC. They appreciate the changes in progress, and they want more.

They live with a difficult chronic illness. They are frequently discriminated against because of people's fears and prejudices, the biggest of which is that people with a mental illness are violent and don't recover.

People with a mental illness want to recover and live well in the community. To do this they need three things: more respect from their fellow citizens, more sensitive and appropriate care, and more accountable movement towards a community mental health system.

This report outlines for the Minister of Health some basic actions government, health authorities, mental health advocacy groups and communities can take to make improvements in the health of the mentally ill. The recommendations derive from what people living with mental illness told the Advocate in the first year of the service.

That people experience difficulty should not be taken personally by providers. It is a reality of the situation we are all working hard to address. The people's comments give us future directions for change. While I observe difficulties, I have also tried to acknowledge the progress that is being made.

It has been a great honour to be the first Mental Health Advocate of BC. It is also the hardest job I have ever done. Since initiating the office in October 1998, I have talked to hundreds of British Columbians facing difficulties in living well with a mental illness. I have traveled and visited people in large and small communities throughout the province, from the Mile Zero Hotel in Dawson Creek to the Vancouver Jail. It distresses me greatly that some of the mentally ill people waiting for services are in our correctional system, and I ask those who engage in discussions about health care wait lists to recognize this fact.

Finally, I would like to acknowledge the inspiration of my brother and my mother. Their courage in the face of continuing adversity, like that of the other 643,000 British Columbians who suffered from a mental illness in the past year and the estimated 1,286,000 citizens who care for them, is the reason I am here.

Respectfully submitted,

Nancy Hall

Nancy Hall, Ph.D.
Mental Health Advocate of B.C.

Introduction

The Office of the Mental Health Advocate was launched in October 1998 as one of the actions resulting from the Mental Health Plan released in January of that year.

The responsibilities outlined for the Advocate were:

- To provide systemic advocacy throughout the province of British Columbia in order to improve the quality of life of people living with mental illness
- To comment to the Ministry and Health Authorities on acceptable and uniform levels of mental health care standards and regional service systems throughout the province
- To advise government ministries which provide services to people with mental illness (e.g. Social Development and Economic Security, Health, and Attorney General) on improving the systems of care for persons disabled with serious mental illness
- To facilitate the establishment of a framework for effective and efficient individual advocacy.
- To research priorities from the individual advocacy networks to identify which service system issues need to be addressed
- To provide a referral source for individual advocacy issues
- To provide education and information to individual advocates and the public
- To report annually to the Ministry, or more frequently if required, on systemic advocacy issues and the state of mental health in regions of British Columbia
- To liaise with other Provincial Advocacy Offices including the Child, Youth and Family Advocate, the Advocate for Service Quality, the Office for Disability Issues and the Provincial Health Officer
- To liaise with the Provincial Health Officer regarding the mental health status of British Columbians

To accomplish these goals, the Mental Health Advocate of BC set the following objectives for year one:

- To establish the Office and with it a confidential means for individuals with mental illness and their families, friends and care givers to contact the Advocate
- To visit communities and provincial service systems to learn how the system operates and what systemic improvements are required
- To build connections for change

These activities were carried out with a view towards recommending a more specific mandate, operating structure and appropriate resources for the Office for subsequent years.

This document comprises a summary of the actions and experiences of the Office of the provincial Mental Health Advocate for the first year of operation, and suggests key recommendations for change.

The Office of the Mental Health Advocate was launched in October 1998 as one of the actions resulting from the Mental Health Plan released in January of that year.

Executive Summary

Dignity is central because it is the foundation for self-respect, and without self-respect, recovery is impossible.

This is the year-end report of the Mental Health Advocate of British Columbia.

This Office was created in October 1998, as recommended by the Ombudsman of BC in the 1994 report, "*Listening*," and acted upon by government in announcing its 1998 Mental Health Plan.

According to the Mental Health Plan, the Office was to:

- Act as a single point of information and referral for persons with a mental illness and their families
- Report on the state of the mental health system
- Ensure that services are integrated, co-ordinated and non discriminatory

The process of establishing the Advocate's office is well underway, with a series of critical meetings and discussions with related organizations throughout BC having taken place, and continuing to take place. Information and referral systems have also been established. Between January 1 and December 31, 1999, the Office had 857 contacts with 630 British Columbians who wanted information or referrals to cope with their own mental illness or that of a family member or client.

Chapter 2 of this report summarizes the concerns people raised with the Advocate. Thirty-three percent of the contacts to the office related to difficulties in accessing care. Often people didn't know how to express the problem or if indeed they had a problem. People's problems didn't fit with the way care is currently organized. As emergency services are frequently the person's first point of contact with the treatment system, it is important that trained and sensitive care providers greet patients in crisis in settings best suited to psychiatric emergencies. Currently, competent emergency mental health services are not uniformly available around the province.

People's concerns and complaints show that successful community living for people with psychiatric disabilities requires attention to more than simply health care services. Approximately one in five contacts to the Advocate related to problems with the BC Benefits program or private insurance benefits. A further fourteen percent of contacts reported frustration with access to safe and affordable housing. Eighteen percent of contacts related to difficulties mentally ill people have in coping with legal encounters pertaining either to involuntary committal or to Criminal Code, child custody or property issues.

The recommendations in Chapter 3 are based upon what people told the Advocate through individual communications at group meetings and during site visits. There are three basic recommendations, with a number of specific actions that can be taken by the Ministry of Health, health authorities, physicians, the Minister's Advisory Council on Mental Health, Regional Mental Health Advisory Councils and communities. The key recommendations are:

• FOSTER DIGNITY FOR PERSONS LIVING WITH A MENTAL ILLNESS

Dignity is central because it is the foundation for self-respect, and without self-respect, recovery is impossible. This report recommends that dignity would be enhanced by anti-stigma campaigns and education to address emotional literacy. Dignity would also be fostered by more systematic attention to income assistance and housing for people with psychiatric disabilities. Self-respect would grow if the care system acknowledged trauma as a reality in a mental patient's life and made efforts to minimize additional trauma in the care process. Finally, to enhance dignity, access to individual advocacy needs to be strengthened. Access is not universal in this province. A strengthened commitment to individual mental health advocacy in the health authorities and at Forensic Psychiatric Institute would act as a bridge to care and would support enhanced community living for individuals with unique lives and complicated conditions. More visible and independent complaints management processes at the regional level and formal investigative protocols for the Advocate, the MoH and the health authorities would make it easier for patients and families to self-advocate.

• CREATE MORE UNIFORM AND SENSITIVE MENTAL HEALTH CARE

The recommendations relating to care begin with outlining the necessity for provincial standards for mental health care in a devolved, regionalized health care system. Implicit in standards for care are standards for patient rights. There is also a need to continue with provincial initiatives to address early intervention, emergency services, mentally disordered offenders and the needs of the seriously or persistently ill in a more responsive fashion. Part of making the system more sensitive to the needs of the mentally ill is to continue to capitalize on the unique experiences of "those who have been there" and strengthen the role of consumers as providers in the system. Before proceeding with programming in this sensitive area, the Advocate recommends a working group scope out the policy lessons from other jurisdictions.

• CREATE STRONGER CO-MANAGEMENT OF THE MENTAL HEALTH PLAN

The recommendations pertaining to stronger management ask that the commitments of the 1998 Mental Health Plan be translated into an achievable multi-year plan with specific objectives and measurable targets. Recognizing that the health of people with psychiatric disabilities involves policies and actions in several government ministries, the Advocate asks for the participation of senior staff from the Ministries of Social Development and Economic Security, the Attorney General, Children and Families and Education, Skills and Training in Mental Health Plan Implementation management activities. Recognizing that physician services represent almost $107 million of public spending on the mentally ill, the Advocate also asks that the doctors of this province who provide mental health care coordinate their activities as part of the Mental Health Plan Implementation process. Finally, as the care delivery system is regionalized, stronger management of the Mental Health Plan will have to evolve to represent a collaboration between Regions, the Ministry of Health, related government Ministries, private practitioners and consumers and families.

In Chapter 4, the Conclusions begin with acknowledging that progress is being made but that the complaints from the users of the system suggest more focused and intensive mental health reform efforts are necessary.

The regionalized system of delivery requires a different collaborative process, led by the Ministry of Health, than has existed to date. This process has to balance 4 paradoxes:

- Mental illnesses are not all the same. Some people are seriously and persistently ill; others recover with minimum intervention.
- Leadership must be simultaneously top down and bottom up.
- There is more to health than health care. The system must balance the need for improved health services with that of providing support for community living.
- Care must be respectful and empowering in its approach, although sometimes coercion is required.

The variety of concerns raised to the Advocate's Office in the first year underlines the importance of the role of advocates at the regional and provincial levels in listening and in balancing these paradoxes and the tensions arising from them.

The Advocate concludes by asking the Ministry of Health to develop a Phase 2 Mental Health Plan and create a Mental Health Commission to monitor the Plan's implementation. Finally, as change is a process that takes place through dialogue, the Advocate recommends that this report be discussed by the Minister of Health, Ministry of Health executives, the Minister's Advisory Council on Mental Health, the Regional Directors of Mental Health, and consumers, families and community organizations. As a number of recommendations would require action by other Ministries, the Advocate also asks the Ministers of Social Development and Economic Security and Children and Families and the Attorney General to review this report and strengthen the collaborative process with the Mental Health Plan.

The Advocate concludes by asking the Ministry of Health to develop a Phase 2 Mental Health Plan and create a Mental Health Commission to monitor the Plan's implementation.

Chapter①

Overview of the Office and Its Function During its First Year of Operation

Establishing the Office required setting up the necessary systems and networks for information and referral, consulting with the regional health authorities, and conducting service audits. As the Advocate was to represent the needs of people who have experienced mental illness throughout the province, she met with consumers, families and front line service providers in a variety of settings. The Advocate also held several meetings focused specifically on mental health advocacy, getting suggestions as to the best way to facilitate this function across the province.

In addition to "community conversations," the Advocate also spoke at a variety of education sessions with community members and professionals in a variety of sectors.

1.1 Office set up

Once an Office was set up at 905–207 West Hastings, Vancouver, systems for information and referral were established, including a database of mental health system resources organized by health region. This resources database currently contains over 1900 names.

A second database was established to systematically track contacts by the public to the Office and subsequent referrals to provincial groups, community agencies or Health Authorities. The data was later summarized for this report.[1]

A brochure with information about the role of the Mental Health Advocate and other referral sources in the mental health community was developed and 10,000 copies distributed to Regional Health Authorities, public libraries, MLA's offices, hospitals, and advocacy agencies throughout BC.

A website with a searchable database was established at www.mhadvocate.com.

1.2 Network development

In order to create an advocacy network and to facilitate referrals, the Advocate developed a comprehensive inventory of existing organizations related to mental health services, and these were entered into a resources database. Contacts include:

- Provincial mental health staff
- Provincial advocacy agencies
- Provincial oversight bodies (Ombudsman's Office, the Privacy Commissioner, the Coroner, the Child and Youth Advocate)
- Provincial programs for specific needs (e.g. Integrative Personality Program at Vancouver Hospital)
- Regional Health Authority CEOs and staff
- Regional contacts for complaints management
- Regional Mental Health Directors
- Anti-Poverty advocates
- Multicultural service agencies
- Aboriginal health agencies
- Forensic/correctional system services
- BC Schizophrenia Society (BCSS) Representatives

- Canadian Mental Health Association (CMHA) branches
- Mental Health Action Research and Advocacy Association staff
- Local consumer and family advocates

Peer advocates were personally contacted to verify that they wished to be included in the database and that this information could be shared with others in the mental health system.

As part of network building, the Office provided the database to the Mental Patients' Association to aid in forming an Income Assistance mailing list, and to the CMHA to aid in conducting research on the function of peer advocates.

Two other initiatives towards network building organized by the Advocate's office brought together people working on specific concerns. A series of roundtables on income and benefits was held between February and June 1999, and a roundtable on women's mental health issues is scheduled for February 18, 2000. Additional roundtables are planned for children and youth mental health and housing issues.

1.3 Referrals

In the period January 1–December 31, 1999, there were 857 contacts to the Office. The people who called were listened to, their information recorded for future analysis, and then most callers were referred.

Five hundred forty-eight individuals received at least one referral. The majority of people who did not get a referral were either in a situation where there was no one to refer them to or, more commonly, they were just phoning to "let us know."

In total, the Office made 677 referrals to other agencies. The largest number (471) was made to community agencies and advocates. The second largest number (120) was made to regional health authorities. The emphasis on community agencies and advocates stems from the fact that the majority of contacts who wanted a referral had already exhausted local complaints processes.

All 37 complaints regarding care at Riverview Hospital were referred to the Riverview Advocacy Program. All 43 regarding care at Forensic Psychiatric Institute (FPI) were referred to the FPI Administration.

The Advocate's Office referred 76 people to the Income Advocates of the Mental Patients' Association's Mental Health Empowerment Advocates Program, plus 14 people to the same advocate working at the BC Coalition of People with Disabilities, which has a toll-free number. As well, the Office referred 70 people to other welfare/poverty advocates or local advocates who help with income issues outside the Lower Mainland.

The Office referred 12 individuals to the Community Legal Assistance Society for mental health law consultation and 13 people to the Mental Health Law program for help with Review Panels. In addition, the Office referred 47 people to Vancouver Legal Services and a further 45 people to various community Legal Aid agencies outside Vancouver.

1.4 Regional consultations

The Advocate received many invitations from BC communities to meet with consumers, their families, advocates, service providers, Regional Directors, forensic staff, regional management and Health Board governors. The table at right lists the various communities that the Advocate has visited. Further visits are in the planning stages. Most visits featured a combination of meetings with providers and local advocates as well as visits to housing, hospital, community mental health and rehabilitation programs, and "community conversations" with consumers and families.

These visits had three main goals:
- To learn about the community's issues and to build capacity for people to advocate for their own needs
- To develop a local network for future contact from the Advocate's Office with the mental health directors, managers and advocates
- To audit the service system and to understand the system's strengths and weaknesses from the perspectives of both the person(s) living with a mental illness and the front line care provider

1.5 Orientation visits and service audits

In order to be able to refer appropriately and to

The Advocate visited these communities Nov 1998 – Nov 1999

Abbotsford
Burnaby
Chilliwack
Cranbrook
Dawson Creek
Delta
Duncan
Ft. St. John
Kamloops
Kelowna
Langley
Nanaimo
New Westminster
North Vancouver
Penticton
Port Coquitlam
Richmond
Sechelt
Squamish
Surrey
Terrace
Trail
Vancouver
Vernon
Victoria
White Rock
Williams Lake

Advocacy is: the act of speaking in support of human concerns or needs. Where people have their own voice, advocacy means making sure they are heard: when they have difficulty in speaking, it means providing help; where they have no voice, it means speaking for them.

Making Changes: A Place to Start – BC Ministry for Children and Families

advocate for systemic change, the Advocate had to have an understanding of the various agencies in the system, how they related to one another from the patient's perspective, and what services they provided.

To accomplish this, the Advocate met with representatives from provincial services and advocacy agencies to review their mandates and responsibilities to the mentally ill.

The provincial services the advocate met with include:
- The Provincial Coroner
- The Ombudsman of BC and staff
- The Information and Privacy Commissioner and staff
- The Child, Youth and Family Advocate, Ministry for Children and Families (MCF)
- The Advocate for Service Quality (MCF)
- The Provincial Health Officer
- The Public Trustee for British Columbia
- The BC Review Board Chair
- Staff at the Ministry of Health (MoH)
- The BC Mental Health Review Panel Chair

The advocacy agencies the Advocate visited include:
- Community Legal Assistance Society
- Canadian Mental Health Association– BC Division
- BC Schizophrenia Society
- BC Association for Community Living
- Mental Patients' Association
- Kettle Friendship Society
- Mental Health Action Research & Advocacy Association
- Coast Foundation

The Advocate also made orientation visits to:
- Riverview Hospital
- Forensic Psychiatric Institute (FPI)
- Forensic Assessment Unit, Vancouver Jail
- Vancouver Courthouse
- Victoria Forensic Community Clinic
- Vancouver Hospital
- St. Paul's Hospital
- Eric Martin Pavilion, Royal Jubilee Hospital, Victoria

In addition, the Advocate made service audits in a number of Health Regions. These audits were conducted to help the Advocate see how a patient might flow through a regional/ provincial service system, including after-hours emergency services, hospitals, community mental health centres, forensic clinics, residential facilities, shelters and transitional housing, clubhouses and community rehabilitation programs. The purpose was to look for movement towards recovery and places where people did not "flow" towards better health. The audits helped identify difficulties experienced by both front line staff and consumers in these settings.

Service audits were conducted in the following Health Regions:
- Coast Garibaldi
- Cariboo
- North West
- Thompson
- Vancouver/Richmond
- Fraser Valley
- Okanagan Similkameen

1.6 Meetings with consumers, families and communities

The Advocate held meetings with consumers, families, community members in general and Regional Mental Health Advisory Committees.

Consumer meetings: These gatherings usually took place in environments that consumers considered non-threatening, such as a clubhouse (Langley, Nanaimo, Duncan, Abbottsford, Sechelt, Squamish, Riverview Hospital, Coast Drop-In in Vancouver, Kettle Friendship Centre in Vancouver, Terrace, Dawson Creek), a community office (Williams Lake) or a church multipurpose room (Kamloops). The meetings began with the Advocate explaining her role and mandate and very quickly progressed to an open conversation.

Family meetings: The Advocate attended meetings organized by the regional representatives of the BC Schizophrenia Society in Victoria, Kelowna, Kamloops and Sechelt. These meetings took place in a clubhouse, a church multipurpose room or a hotel meeting room. As in the meetings with consumers, these began with the Advocate explaining her role and mandate and very quickly progressed to an open conversation.

Community meetings: The Advocate spoke to Annual Meetings of CMHA branches (Vancouver, White Rock) as well as a number of general

community meetings or "Community Conversations" (Vernon, Duncan, Ft. St. John, Dawson Creek, Burnaby, New Westminster, Williams Lake and Abbotsford). The meetings typically involved a brief address by the Advocate, followed by active question and answer sessions. The meetings were attended by individuals with a variety of interests, including consumers, family members, providers and community agency representatives. Inevitably, each meeting brought out people who were new to life in the mental health system. Because local advocates attended, all meetings had an element of mutual aid.

Regional Mental Health Advisories: The Advocate met with Regional and community Mental Health Advisory Committees in Central Vancouver Island (Duncan), Coast Garibaldi (Squamish), North Okanagan (Vernon), Peace Liard (Ft. St. John, Dawson Creek), Simon Fraser (Burnaby, New Westminster), South Fraser (Langley, Surrey, White Rock, Delta), North Shore (North Vancouver), Vancouver, Richmond, North West (Terrace) and Thompson (Kamloops). These meetings were exploratory, giving the Advocate a chance to learn of local issues and local leaders a chance to meet the Advocate.

1.7 Consultations on advocacy

Part of the Advocate's mandate was to develop a framework for advocacy. To accomplish this, the Advocate held two roundtable consultations on Mental Health Advocacy. Participants in each meeting were asked to identify priority advocacy issues and contribute their ideas for a vision of the ideal process/structure for mental health advocacy in British Columbia.

The Lower Mainland and Fraser Valley group met in Vancouver on March 26, 1999. Thirty-six people attended. The Vancouver Island Group met at Providence Farm near Duncan on May 10, 1999. Thirty-eight participants attended. Findings from these meetings are detailed later in this report.

A number of other advocacy round tables were planned, to take place in various regions, but funding was not available for travel costs of participants in rural areas. In July 1999, the Ministry decided it would take the lead in developing an Advocacy Framework.

1.8 Participation in Mental Health Plan activities

Because the mental health system has been going through a period of reorganization as the Ministry of Health (MoH) moved from a centralized to a regionalized model, the Advocate was asked by the Ministry to participate on the following committees:

- Mental Health Plan Implementation Steering Committee
- Provincial Mental Health Advisory Council Restructuring Reference Group
- Performance Monitoring Framework Reference Group
- Advocacy Framework Reference Group
- Target Population Reference Group
- Bill 22 Reference Group
- BC Provincial Information Management Steering Committee
- Mental Health Evaluation and Community Consultation Unit (MHECCU) Advisory Board

1.9 Education

Part of the Advocate's mandate is to educate both professionals and the community at large about mental illness. Acknowledging the stigma and prejudice that often accompany mental illness, the Advocate developed a stand-alone education message about mental illness to present in community and media settings. The elements of this message are:

- The public does not understand mental illness. They do not understand that in any one year one in five of us may experience a mental disorder.
- People make many false assumptions about people living with a mental illness: that people are lacking in intelligence, that people are violent, that people cannot be good parents and most critically, that people don't recover.
- The prevalence of violence among mentally ill people is no higher than in the rest of the population. The only area where the prevalence is higher is when the mentally ill person has a concurrent addiction.
- People with mental illness can and do recover especially if they are given prompt access to supportive care, housing and employment or income assistance.

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People make many false assumptions about people living with a mental illness: that they are lacking in intelligence, that they are violent, that they cannot be good parents and most critically, that they don't recover.

People with mental illness can and do recover especially if they are given prompt access to supportive care, housing and employment or income assistance.

THE BC MENTAL HEALTH SYSTEM

People with a Mental Illness, their Families and Friends

Peer Advocates

Non-profit Community Agencies and Societies

Family Doctors/Psychiatrists

Ministry of Health

Regional Health Authorities

Riverview

Forensic Psychiatric Institute

Correctional Services

Mental Health Evaluation and Community Consultation Unit (UBC)

Also includes:

Ministry of Social Development and Economic Security

Ministry of Education, Skills and Training

Ministry for Children and Families

Ministry of the Attorney General

Police/RCMP

Workplaces, Unions, WCB

Legal Services

Poverty Advocates

Professional Associations and Regulatory Bodies

The Advocate presented at a number of specific workshops and educational sessions for community members including:

- Patient Rights Workshop, a keynote presentation to a community workshop on Rights of the Mentally Ill, sponsored by the Regional Mental Health Advisory Committee in Cranbrook, October 1998
- Guardianship Workshop, Burnaby, November 1998
- Family Education Day, Riverview Hospital, February 1999
- "Erase the Stigma," a keynote address to a Community Education event held in Burnaby, March 1999
- "Partnership in Action," a keynote address to a consumer and family planning workshop for the Capital Region held at Dunsmuir Lodge, March 1999
- SHARE Annual General Meeting, a keynote address to a strategic planning session for a non-profit agency that provides services to the mentally ill in Coquitlam, April 1999
- "Patient Education Conference," a panel presentation on housing needs, Riverview Hospital, April 1999
- "Clubhouse Conference," a keynote address to a regional conference of Consumers and Clubhouse Members, Trail, May, 1999
- CMHA National Annual General Meeting, a workshop presentation on Advocacy, Vancouver, August 1999
- Implications of the New Mental Health Act, a keynote presentation to a community meeting on revisions to the Mental Health Act, Vancouver Public Library, November 1999

The Advocate also conducted a number of professional education sessions to raise awareness of the needs of the mentally ill and communicate new improvements in care:

- Panel presentation on the needs of people with mental illness, at Discoverability 2, Ministry of Human Resources, Richmond, March 1999. This presentation led to collaboration with the Office for Disability Issues, and now the program is being delivered around the province, with local mental health consumers participating.
- A series of professional development seminars for nurses working in the mental health system hosted by the Registered Nurses Association of BC Regional Coordinators in Vernon, Penticton and Kelowna, February and September 1999. These presentations focused on the role of the provincial Advocate, the role of nurses as advocates and developments in early intervention approaches. They also provided an invaluable source of local front line opinion leaders who were later contacted on site visits.
- Keynote address on Women's Mental Health Needs from the Perspective of the Mental Health Advocate at the Women and Mental Health Conference for service providers in the mental health system sponsored by the BC Minister of Health's Advisory Council on Women's Health, in Richmond, June 1999.
- Keynote address at the Mental Health and Violence against Women Conference to the staff of the BC Association of Specialized Victim Assistance and Counseling Programs in Richmond, October 1999.
- Keynote address to the Mental Health and the Law: Who is Falling Through the Cracks? workshop for media representatives sponsored by the Canadian Bar Association and the Law Society of BC, Vancouver, November 1999.
- Roundtable discussion with the Downtown East Side community and 30 Provincial and Supreme Court justices at Judicial Community Liaison Program: A Dialogue with Community Agencies and the Downtown East Side. During this session the Advocate was able to raise with the judges the impact of a jail term on a mentally ill person's benefits and housing status.

Advocacy for Mental Health in BC

Provincial Mental Health Advocate

Riverview Hospital Advocates

Mental Health Law Program

Provincial Advocacy Associations:
- Alzheimer Society
- ANAD
- BCSS
- CMHA
- MDA
- Mental Health Action Research & Advocacy Association

Vancouver Advocacy Agencies:
- Coast Foundation
- Mental Patients' Association
- Kettle Friendship Society

Anti-Poverty Advocates

Legal Advocates

Mental Health Empowerment Advocates Program

Regional Advocates*

Advocate at FPI*

Support Groups for Adult Attention Deficit Disorder, Anxiety Disorder, Depression*

Chapter②

Concerns of British Columbians who Contacted the Mental Health Advocate

This chapter details the concerns expressed by people living with mental illness who contacted the Advocate. People expressed their concerns by telephoning the office, attending community meetings with the Advocate, talking to her during regional and provincial service audits, and reporting at advocacy meetings. There is a tendency in medical/administrative culture to dismiss this kind of data as "anecdotal." However, from the Total Quality Management perspective, individual problems aggregated provide themes for change. This chapter outlines these themes, which then serve as the basis for the policy recommendations given in Chapter 3.

2.1 Concerns of people who contacted the Office

People's concerns were listened to, referrals made and the information entered into a confidential database. Five broad categories of concern (Community Care, Hospital/Medical Care, Benefits, Legal and Housing) were identified after analyzing two months of contacts. These categories were chosen to represent sites for systemic change.

There were also a number of calls that did not fall into the above categories. These were classified as "Other." The bulk of the "Other" calls concerned stigma, apprehension of children because of the mother's mental illness, or pertained to the needs of children or youth.

The graph on page 13 shows how the 857 contacts to the office were sorted. Within each category, the data was analyzed for consistent themes, which are described below with examples from people's experiences. A roll-up analysis of individuals' difficulties then identified the systemic issues.

• ACCESS TO COMMUNITY CARE

Reflecting 363 contacts, access to community care was the most common difficulty reported by users or potential users of the system. The many different aspects of access problems are described below.

Lack of knowledge about mental illness and the treatment system

In some cases, individuals thought they or an individual they cared for was suffering from a mental illness and needed to know how they might get an assessment to determine the nature of the problem.

Lack of services to fit the person's needs

The people who contacted the Office often had complicated situations and multiple needs. Some had concurrent disorders of mental illness and addictions; others were both mentally ill and developmentally challenged and moving out of the MCF's service system into the very different level of support from services funded by the MoH. Parents of children with serious mental illness reported difficulties

finding any services post crisis. People in rural areas were very concerned about access to specialist care. The saddest situations involved people who were so disabled they could not even approach the care system, such as a woman who suffered from obsessive compulsive disorder and had not bathed or left the house in three years.

Failure to meet the criteria for service
In other cases, the services existed but the person was told (sometimes incorrectly) that they did not meet the criteria. For example, a woman with acquired brain injury was suffering from serious depression but was not considered "Axis 1" and therefore not eligible for the Community Mental Health Team's services.

Failure to behave according to treatment norms
In some cases, consumers were banned from a service, mostly because their behaviours were considered objectionable or threatening by the service providers. Often, from the person or family member's perspective, the consumer was ill and seeking care, and ended up being punished for his or her symptoms. Several contacts were received from families whose loved one was denied care by the community or hospital system while ill and went on to offend, receive treatment in the forensic system and live with a criminal record for the rest of his or her life.

Access to medications
In some cases, the consumer, family member or service provider was looking for access to newer medications. Most calls related to first line access to either the newer antipsychotic medications or the newer antidepressants. In other cases, individuals did not understand Pharmacare's Special Authority process whereby the person's doctor can make a special application to receive the newer drugs. Adults living with a diagnosis of Attention Deficit Disorder were upset about Pharmacare not covering their medications and special dietary needs.

Difficulty in moving to another region
Portability is a basic condition of Medicare, but in the regionalized system individuals with mental illness often found it difficult to take their benefits from one region to another or in getting the two regions to share clinical information. For example, when a seriously ill client moves to a new community, her care records are not proactively transferred, or when a client moves to another region his rent subsidy is not transferable.

My daughter is addicted to drugs and alcohol on top of her schizophrenia. Drugs and alcohol are symptoms, not causes, but no one will treat her because of her addictions. Must she commit a crime to get services?

• ACCESS TO AND QUALITY OF MEDICAL/HOSPITAL CARE
Access to and quality of medical/hospital care represented the second largest number of calls (231). This area is of primary importance, as research from the BC Early Intervention Study[2] indicates that most people make their initial contact with the system through emergency services. The kinds of issues raised were:

Lack of timely care
The majority of complaints related to hospital care referred to how people were dealt with in a crisis, either as an inpatient or while in private

Concerns of people who contacted the office

I was put in solitary with no lights, no food, no shower. I was given wrong meds and treated abusively. Why should mentally ill people be locked in solitary while in Emergency? There should be crisis beds for them if they're not at risk to anyone.

My boyfriend is paranoid and won't leave the apartment. MSDES won't come to the apartment so he could fill out the forms, so we are both living on my Disability Benefits.

medical or psychological care. (For example: one mother called after her son, having been turned away by the Mental Health Centre and her local GP, tried to strangle her in his psychosis, and ended up a patient in the forensic system.)

Lack of dignified care
People also called the Advocate to complain about receiving hospital care in a less than dignified manner. For example, people phoned to complain about being forcibly medicated or restrained or held in a locked room with no clothes or washroom facilities.

Lack of quality rural emergency care
Serious complaints were received about the quality of emergency care in rural areas. There are 40 general hospitals in communities around BC without any psychiatrists or psychiatric beds. Most are lacking in basic facilities to calm and stabilize a person for transfer to a regional centre. Parents and friends called to complain about the lack of after-hours support and ill people being detained in secure rooms without any washrooms or comforts.

Concerns about lack of coordination
People with a mental illness are perhaps unique among patients receiving medical care in that there is little if any communication between private doctors and hospital doctors in most regions. Electronic records systems are in very early stages of development. The result is that people's medical histories may go untold, or people may have to retell their medical histories over and over again.

Concerns about professional care
Calls were also received complaining about the quality of care received from individual physicians and psychologists. These individuals were referred to the relevant regulatory body.

• ACCESS TO BENEFITS
Two hundred and nine contacts to the Office concerned access to financial assistance and represented the third most common reason for contacting the Advocate. Individuals called with extreme frustration around accessing both the public BC Benefits system and private disability benefits. The Advocate also learned from callers and providers that families often do not do adequate estate planning for their relatives and so inheritances (however small) only serve to disqualify the person from receiving BC Benefits. The kinds of issues raised were:

Difficulties with the process of accessing BC Benefits
For a person with a chronic mental health disability, accessing BC Benefits is a major step towards creating the stability in housing and daily living necessary for recovery.

Applying for BC Benefits, lodged within the Ministry of Social Development and Economic Security (MSDES), was reported to be a very complicated process. For example, people who are paranoid and suspicious of any bureaucratic process don't do well with a process that requires two to three rounds of application and appeals. In fact, the Income Advocates at Mental Patients' Association who took referrals from the Advocate's Office noted that the amount of red tape has gotten worse in the past few years.

There are two levels of Disability Benefits under BC Benefits: Disability 1 (DB1), which pays $596/month, and Disability 2 (DB2), which pays $771/month. Patients living in hospital or in Licensed Care Facilities receive a Comforts Allowance of $82/month. Their shelter and support benefit is paid directly to the facility owner. People on DB2 are those considered the most disabled and in need of support.

Because the policies change on a regular basis without any advance warning to the mental health care system, mental health service providers have called to report spending valuable time responding to patient anxiety over changes and advocating with the MSDES staff.

Complaints about the lack of support for people trying to work or attend school
Some callers complained that the actual amount of the benefit represents a form of "legislated poverty" because of restrictions on the ability to work while in recovery and on Benefits. Those on DB2 are allowed to keep the first $200 of any money they earn; those on DB1 can keep $100. Above this limit, the person is allowed to keep 25% of their earnings.

Complaints about the level of the Benefit
The absolute level of the benefit has not changed since the spring of 1994. Some callers

felt they were forced into substandard housing when faced with trying to find accommodation with a shelter allowance of $325/month. Other callers who lived in community residential facilities or at Riverview and only received the $82/month Comforts Allowance found it hard to live on that amount, especially if they smoked. The Riverview Advocate has approached the Provincial Advocate because of considerable unhappiness among Riverview patients about this issue. The Riverview Advocate was also concerned that someone could be discharged after a long hospitalization with no benefits and no bus pass.

Complaints about the CPP Initiative
The switch of thousands of BC Benefits recipients to the Canadian Pension Plan (CPP) during the 1998-1999 period, though cost effective for government, was enormously trying for disabled persons and their families. There were numerous complaints regarding some individuals receiving a lump sum retroactive payment while other people's lump sum payments were sent directly to the Ministry. Currently, there are issues regarding payment of income tax on the federal CPP and rules for earning additional income, which are different in the federal and provincial systems. A significant number of people with a mental illness are now required to follow the rules of two systems, which complicates their lives.

Difficulties with access to benefits during and after hospitalization
The level of the BC Benefit changes if the person gets sick and is hospitalized or put in jail. The standard $771/month DB2 payment is divided into a $325 shelter allowance and a $446 living allowance. If a person is hospitalized for more than one month, the shelter allowance continues to be paid to the landlord but the living allowance is reduced to the $82/month Comforts Allowance. However, if the person is hospitalized for more than 3 months, the shelter allowance ceases and the person loses his or her housing.

The Advocate's Office was contacted by two people who lost their housing because their shelter allowance was not continued when they were in hospital for four months. These people lost their homes, their furniture and also all of their personal possessions, because the Ministry considers it cheaper to pay for new household items than to pay for storage. Similar disruptions occur to persons with a mental illness who are incarcerated (often for nuisance charges occurring while untreated for their illness), as their benefits cease the moment they are put in jail.

Difficulty meeting nutritional needs
Combinations of psychiatric drugs often influence gastrointestinal function. Some people called to complain about difficulty in getting the Ministry to approve payment for Ensure, a nutritional supplement, or to approve an allowance for a special diet.

Complaints of financial penalties for marrying
Like many other people in our society, people with mental illness sometimes want to marry. However, the BC Benefit is income and asset tested. If two people on DB2 marry, the "two-unit rate" is $68/month/person less than if they were single. If a person enters a relationship in which the spouse's income is over $1271/month, or their combined assets are over $5000, then the disabled person is not eligible for income assistance or ancillary benefits. People want Income Assistance to support their disability independant of whether they are in a relationship or single.

Difficulty with inheritances
There were several complaints from individuals on DB2 who had received a small inheritance, but because the money had not been placed in a discretionary trust and approved by the Ministry, the people were cut off benefits altogether until their assets fell below $3000. Unfortunately, this is a common occurrence.

Difficulty with access to ancillary benefits
The BC Benefit system is more than an income supplement system. It also provides DB2 clients with enhanced medical care, dental care and eligibility for a subsidized bus pass that costs $45/year. Discounted fishing and hunting licenses, access to Provincial Parks and ICBC Insurance can be applied for through the relevant channels.

Callers had complaints about the process of getting or replacing a bus pass. Replacing ID is a frequent task for many who, secondary to their illness, lose their wallets easily. The bus pass benefit is meant to support the easy transporta-

My client's application for discharge under the BC Review Panel was turned down. He was told his rent would be paid while he was in hospital, but this wasn't done. A month later when he was discharged he found he had no apartment and no belongings. He has been crashing with friends ever since. This was his first episode, and his experience has made him very resistant to treatment.

I have been stabilized and cleared to go back to my job in a law office. The people that don't know I was on leave for psychiatric reasons treat me OK, but the people that know treat me like I'm dangerous or freaky. When a lawyer runs down the hall, everyone says, He must be late for Court. When I run, everyone says, She must be manic.

My ex-husband has custody of our children. He is now using my mental health diagnosis to take me to court to deny me visiting rights.

tion of disabled persons who live in the community. It seems the program as designed does not always accomplish this goal.

Regular dental care is important to mentally ill people, as the medications they are prescribed affect their oral health and increase the probability of cavities and gum disease. Unfortunately, the BC Benefits Dental Care Plan pays a maximum of $500 per year for those on DB2. It is possible for the MSDES to grant coverage for "pre-authorized dental services". However, this requires a considerable amount of paperwork. Because of the benefit level, any type of restorative dental work is not an easy option for people covered by BC Benefits. In addition, the master agreement between the BC Dentists Association and the Ministry lapsed in 1995 and many dentists now refuse clients or charge them an additional fee.

Other callers who had switched entirely to the CPP benefit scheme were shocked to find they no longer had access to dental or other benefits described above. This occurred despite a policy directive several years ago saying that people on CPP shouldn't lose any Ministry-sponsored medical coverage. People on CPP are also not eligible for a bus pass.

Difficulty with private disability insurance
Complaints were received from individuals having difficulty accessing private disability benefits. Insurance company physicians have overturned disability ratings by private general practitioners and psychiatrists, leaving the individuals in the difficult position of feeling too sick to work but with no disability income. One woman needed help in challenging an insurance company ruling that disqualified her son's mental illness and with it, her fire insurance claim on her house. Living in a trailer in a campground at the time, she was referred to Legal Aid.

Difficulty with workplaces
Complaints were received from people who had returned to work after stress leave, especially for anxiety and depression. In some cases they were not given supported work commensurate with their disability and their supervisors were reported to be trying to ease them out of their jobs, either overtly or via a "chilly climate". In some cases, people noted that their unions were as unsupportive as were their supervisors. In other cases, even if the union was supportive, the grievance process is extremely lengthy, and in the meantime the person would be unemployed. As depression and anxiety are so common and so treatable, it is vitally important that management and labour unions develop a better understanding of these more common mental illnesses.

• ACCESS TO LEGAL SUPPORT
One hundred sixty-two contacts were made to the Office concerning access to legal support. Individuals called regarding basic rights while they were involuntarily in hospital, or needing access to legal support to deal with property ownership or access to children. Some caregivers called to complain that the Review Panel process recognizes Charter rights above the right to care. Other caregivers called to get assistance in dealing with the forensic system.

• ACCESS TO HOUSING
Eighty-three contacts concerned housing. Most of these were about the long waiting lists to get into group homes or other subsidized or supported housing. In some communities, appropriate housing for people with a mental illness diagnosis is non-existent. One woman told the office that her daughter, in her 20s, was housed with Alzheimer's patients because of lack of facilities in her community.

2.2 Concerns identified through meeting with consumers, families and communities

Several themes recurred in meetings with consumers:
- Lack of respect and dignity from care providers, police and the community in general
- Concern for privacy, confidentiality and basic rights as a psychiatric patient
- Fear about the revisions to the Mental Health Act, particularly the extended leave provisions
- Frustration with the poverty that comes with mental illness and issues with the BC Benefits system
- Need for more housing
- Lack of understanding of how the regionalized system works and how to influence change

Several themes recurred in meetings with families:
- Grief of dealing with a seriously ill relative
- Frustration with an inadequate service system

- Frustration at not being respected as a primary care provider by doctors and nurses
- Frustration regarding their relatives' access to newer medications
- Needing to understand the revisions to the Mental Health Act and what to expect from local providers
- Frustration with changes to the regional mental health system
- Lack of understanding of how the regionalized system works and how to influence change

Several themes recurred in community meetings:
- How to improve access to help for ill people
- The different manifestations of mental illness and the need for society to develop better understanding so that people with serious needs can get treatment sooner and experience less stigma
- Care failures that lead to people winding up in the forensic system
- Barriers to education and employment for people recovering from mental illness
- Access to specialist care, particularly secondary or tertiary hospital beds in the rural and northern health regions
- Mental Health Plan activities

Some people indicated they valued meeting the Advocate, as it was hard for them to complain in the regional system because it was the only care system they or their ill relative had, and it was easy to be labeled as a difficult person and thereby marginalized.

2.3 Concerns identified through Regional Service Audits

When learning about the elements of the mental health system, it quickly became clear that in fact there were at least 18 different mental health systems being played out in the regions. Based on the Advocate's visits and discussions, the following issues were identified:

Regional structures for care delivery
The creation of a single point of accountability for mental health in the health care delivery system is a standard for best practice.[3] Unfortunately, not all regions have reached this state of integrated management. Community-based mental health services are integrated in regional mental health structures in 16 of the 18 Health Authorities. Hospital-based mental health care is integrated with community mental health in 10 of the 18 regions.[4] The integration and reorganization of services is time consuming yet important work that needs to be supported.

The Mental Health Service system until recently allocated one-third of its budget to contracted services, particularly for outreach activities. With integration, some regions are repatriating contracts. This is having significant impact on local non-profits' ability to remain active and on the options available to consumers and families.

The lack of a regional perspective is most pronounced in some rural areas, where often progress towards integration is complicated by numerous Community Health Councils needing to come together with a Community Health Service Society. One rural Regional Director noted to the Advocate that currently there are 22 different employers in his health region responsible for mental health service delivery.

Regional structures for consumer and family participation
Many consumers and families expressed concern that, with the demise of old provincial advisory structures, their voices have been lost. While the Advocate advised the Ministry in restructuring the Provincial Mental Health Advisory Council, she also undertook a survey of all of the health regions and whether or not they had developed Regional Mental Health Advisory Councils (RMHACs).

Because these groups were in various stages of development, the evaluation assessed process rather than outcomes and was undertaken in the spirit of strengthening the diverse groups around the province. It is of concern however that two regions do not have a structure for consumers and families to give advice at the regional level.

The survey was presented to the Ministry of Health and the Regional Mental Health Directors with recommendations for change, including making the approval of the Region's Mental Health Plan by the RMHACs a standard for receiving mental health funding from MoH. The report is available on our website: www.mhadvocate.com.

As a social worker, I have grave concern about the holding room (in my local hospital). All that patients are provided is a mattress on the floor, no sink, toilet, no blanket or pillow, no books or magazines allowed. Clients have to go to the bathroom in a styrofoam cup.

The doctors won't give me any information about my child's illness and won't listen to my information. I think doctors should respect my role as primary caregiver and want to hear about my child's psychiatric history.

Rural emergency services
The Advocate took her concerns about the quality of rural emergency care to the MoH, which then announced a one-time funding initiative of $1,000,000 to renovate "secure rooms" in ten rural hospitals and to provide training for staff. The initiative was received with mixed reviews, as many small hospitals were concerned they would be expected to provide an increased level of service to mentally ill people with no increase in operational funding. As of February 8, 2000, eight hospitals have decided to participate in this project. There should be no difference in an emergency services provider's ability to care for physical or psychiatric emergencies.

Mediation
In addition to calls about personal concerns, the Advocate also received calls from people in four regions expressing concerns about programmatic issues. In two cases, the Advocate was able to meet with interested parties (consumers, family members, service providers, and Regional Health Authority staff) and provide support to the Regional Mental Health Director in constructing an informal mediated solution.

In other jurisdictions, provincial advocacy offices have investigative powers to address systems issues. In retrospect, having a clear mandate about the ability to engage in mediation or investigation as required would have been useful.

This process also highlighted that regional complaint management systems vary in their visibility and independence. People were frustrated at registering a complaint about a Regional Director's management decision only to be referred back to that same Director by the MoH or by the regional administration.

Regional quality assurance
The Advocate's database can produce reports on a regional basis, with the callers' confidentiality protected, which can serve the Regional Mental Health Director as a very direct quality improvement tool. The Advocate piloted meeting with Directors in five separate regions to present regional information on complaints. Directors were very positive about this process and noted that it served them to reflect on systemic issues in their own health authority.

2.4 Concerns identified through Provincial Service audits

As described earlier, the Advocate participated in a number of mental health systems development projects: the Mental Health Information Management Project; the Performance Monitoring Framework Project; the discussion paper on the Target Population; the renewal and expansion of the provincial psychiatric outreach program, the MHECCU. In addition the Advocate supported the Advocacy Program at Riverview Hospital and and gained understanding of the Forensic/Correctional system and its impact on the mentally ill in BC. The Advocate also studied provincial service systems to see how providers might interconnect, with a view towards better patient care.

Riverview Hospital
Riverview Hospital is the Province's 800-bed psychiatric hospital. It represents for some an acute crisis stabilization unit, for others, a place for a 60-90 day stay to get a specialist opinion on a troubling experience, and for others a long-term safe haven. Since 1996, the downsizing of Riverview has been halted. New programs with the Regions to increase their access to Riverview have resulted in the moving of 60 long stay people to the community mental health system. Many of the cottages on the pastoral Riverview grounds have been renovated for "Step Down Programs" and transitional housing. A new Board has been announced and a search for a CEO has been initiated.

But despite the fact that Riverview has decided not to downsize, regions still have plans to repatriate tertiary services. Administrators in the rural and northern areas have concerns about access to specialist help and beds for ill people in their regions. The approval of the next development stage in the construction of an 88 bed facility in Kamloops means better care for people in the Thompson, Okanagan, Kootenay and Cariboo regions and an opportunity for the mental health community in Kamloops to become a Centre of Excellence for Mental Health. The Advocate visited Kamloops to talk with the Project Manager and view the plans for the new facility.

Faced with individuals needing hands-on help, the Advocate approached Riverview about increasing advocacy services for patients. The Administration had partially implemented the Ombudsman's recommendations by establishing a Systemic Advocate. However, the Provincial Advocate found patients contacting her for individual advocacy concerns and raised this with Administration. Funding for an individual Advocate was added so that the Advocacy Service at Riverview run by the Mental Patients' Association now includes 2.5 people who provide both systemic and individual advocacy for residents. The Provincial Advocate meets on a regular basis with the Riverview Advocacy program to share issues and concerns.

The Forensic/Correctional systems

In November 1998, the government of BC approved the creation of the Forensic Psychiatric Services Commission to oversee the delivery of forensic psychiatric services to the courts. The Forensic System includes FPI, six regional Forensic Community Clinics, and three cottages at Riverview. The Forensic Commission is currently in the midst of a seven-year transition. The Mental Health Plan recommended that FPI be brought under the operating responsibility of Riverview and the responsibility for the regional clinics be transferred to the relevant Health Authorities. This transfer appears to have halted, and the Forensic Commission has recently been presented with an organizational review that includes recommendations for a new administrative structure. The immediate plan is for the clinics to remain attached to FPI.

Unfortunately, the forensic/correctional systems are the default mental health system for many clients. Mental Health Centres and hospitals can and do turn patients away, but jails are always available. Actions in both systems are dictated by the Criminal Code and other statutes such as the Forensic Psychiatry Act. These systems are fluid and change with Court decisions on Charter of Rights challenges and resultant changes in BC Review Board discharge rulings.

A major focus of the initial Mental Health Plan funding was $2.1 million for 30 forensic liaison workers around the province and a further $2.7 million for housing for mentally disordered offenders. The aim of this initiative is to divert mentally ill people from the criminal justice system. A further initiative saw the opening of the Vancouver Pretrial Centre as a 13-bed forensic hospital in the Vancouver Jail.

These are important commitments and it seemed crucial to the Advocate to take time to familiarize herself with the new initiatives before making any recommendations.

The Advocate developed a strong working relationship with the Administration of FPI in order to be able to assist families in understanding what had happened to their relative and where in the system their family member was located. However, the Advocate had no mechanism to address the needs of clients with regards to social rights advocacy (privacy, confidentiality, stigma issues) or therapeutic advocacy (choice of provider, medication, housing or rehabilitation programs).

In response to what was reported by consumers and family members, the Advocate wrote the MoH to request they monitor the number of people who are denied service by the Regional Mental Health system and end up in the forensic system. The Advocate also wrote the Forensic Commission to request that they consider providing an individual advocacy service to clients who find themselves in the forensic system.

Pharmacare

Pharmacare is the MoH Drug Benefit plan. People with psychiatric disabilities receive free coverage for their medication. The choice of medication is an issue. The Advocate received many calls from people wanting first line access to the new atypical anti-psychotic drugs. The Ministry reported there was insignificant evidence to proceed with that policy. Noting that often concerns in the community are informed by drug companies rather than by scientific evidence, the Advocate wrote Pharmacare suggesting a continuing forum where families, consumers, psychiatrists and administrators could review current psychiatric drug literature to develop an evidence-based approach together. It is vitally important that the drug policy for supporting the Mental Health Plan is evidence-based.

My son was turned away from care because the Mental Health Centre and his private GP considered him too sick. In his psychosis, he assaulted me. Now he's at FPI and I am having to act as his advocate at the same time as I am his victim.

The central and most controversial point was the role of coercion in the treatment system. Relatives of ill people, typically with schizophrenia, tended to see their family member as having little insight into his or her illness and requiring compulsory treatment.

As an advocate, I've noticed there's a significant difference between what family advocates think consumers need versus what consumers tell me they need.

BC Benefits Program
Seriously ill people have a great deal of difficulty with the BC Benefits system. The impact of the switch of large numbers of people from BC Benefits to the Canada Pension Plan or a combination of BC Benefits and CPP premiums needs to be evaluated. Despite good will and expressed intentions to improve the process on the part of the MSDES systems managers, the Advocate's discussions with them often seemed at cross-purposes. In 1999, the MSDES commissioned a study to improve income support services for people with serious mental illness but it did not consult with the Advocate and the report does not address the fundamental issues raised by clients contacting the Advocate's Office.[5]

2.5 Concerns identified through advocacy meetings

Advocates contacted the Provincial Advocate through the Office, through informal contact in community visits and through the two Advocacy Brainstorms the Advocate organized. Following are summary comments of issues raised in discussions.

Advocacy from whose perspective?
Self-advocates, peer advocates and formal advocates for people with mental illness did not always have the same perspective as family advocates. This was raised over and over again.

The central and most controversial point was the role of coercion in the treatment system. Relatives of ill people, typicaliy with schizophrenia, tended to see their family member as having little insight into his or her illness and requiring compulsory treatment. Consumer advocates, on the other hand, tended to see that building awareness and a sense of control over one's own illness was possible and vital to the recovery process. They saw coercion as a strategy that reduces self-esteem and dignity and ultimately drives people out of the treatment system.

Of course, neither side is totally right, but in the past year those advocating sticks (in contrast to carrots) seemed to have a stronger voice. Consumer advocates were very concerned about the amendments to the Mental Health Act (Bill 22) that enabled outpatient commitment. This legislation was passed just before the Provincial Advocate was appointed and proclaimed on November 15, 1999.

Both consumer and family advocates recognized that the divisions in perspective were counter productive, and some have come together to form the BC Mental Health Monitoring Coalition. Still, there is much distrust in the community over the issue of coercion. This distrust is counterproductive, but deeply rooted in different values and experiences with mental illness.

Advocacy as a right
Advocates commented that in BC a person with a mental illness has varying rights to access advocacy. For example, all patients at Riverview Hospital now have the right to access an advocate, but patients at FPI do not. Community members in Vancouver and the Central Okanagan have the right to access an advocate, but those in other Health Authorities do not. Patient Rights Advocates have the right to talk to involuntary patients at St Paul's Hospital, Surrey Memorial Hospital, Riverview Hospital and FPI but not at Vancouver Hospital. Even peer advocates who want to attend a medical/mental health appointment with a mentally ill person are variously permitted or refused.

The BC Schizophrenia Society's Regional Representatives form the only recognized provincial system of advocates, and their focus is primarily support for family members. The Mental Health Empowerment Advocates (formerly with the BC Coalition of People with Disabilities), who provide advocacy for accessing the BC Benefits Program, are now lodged with the Mental Patients' Association, which is a regional Advocacy and Service group. Access to Income Advocates in rural areas needs to be improved.

Advocacy around the determinants of health
The agenda of the Mental Health Plan Implementation Steering Committee reflects a tendency for the MoH and Regional Health Authorities to make the provision of health services the primary focus of their support system to the mentally ill. Advocates report that most of the practical work in communities to assist individuals suffering from a mental illness

addresses such determinants of health as poverty, access to benefits, housing and social support... as well as access to care.

Advocacy for culturally competent services
The mental health system is aware it needs to be more culturally competent, but services still have a way to go. Advocates report that they often have to bridge cultural differences between the system and the person with a mental illness. Some advocates suggested anti-racism training as a higher priority than translating brochures.

Addressing the needs of the Aboriginal communities was a common theme to many meetings and the Advocate looks forward to the Aboriginal Mental Health Plan, which is in development. Advocates also noted the positive actions for women's mental health, such as the initiative relating to meeting the needs of mentally ill parents and the training for workers in the women-serving agencies.

Advocacy for fairness and respectful treatment
Community advocates found themselves supporting someone who, in addition to the specific problem, faced the effects of stigma and discrimination that is so often the lot of psychiatric patients. While violent incidents are frequently cited as a problem contributing to low staff morale, they are rarely acknowledged as being formative in a person's treatment history.

One survey reported that 47% of ill consumers refused to contact a clinic due to the trauma of hospitalization.[6]

Community advocates noted that without visible formal complaints processes and protocols for investigation, addressing fairness and respectful treatment is often difficult. Peer advocates noted they could only go so far.

Advocacy for consumer and family participation in regional and provincial planning processes
The Advocates were quick to report if they felt their regional process for input was functional (or not). People were disturbed that the old advisory processes were terminated before the new Provincial Advisory Council was implemented. Advocates were also quick to note that consumers have been absent from the Mental Health Plan Implementation Steering Committee, leaving only the Provincial Advocate to represent consumer issues in this planning forum.

Accountability of advocates
The Community Advocates noted that most keep very primitive statistics of whom they helped with what problems. Several people suggested there should be formal protocols requiring those funded to do individual advocacy to report to the Provincial Advocate so that systemic observations could be formulated.

Advocacy training
Many people raised the need for the training of advocates and for educating service providers about how to work with advocates. Advocacy training has been worked on in the child and youth field by the Penticton Advocacy Network, with support from the MCF, the Ministry of Human Resources and the Community Law Foundation.[7] At present, the only Mental Health Advocacy training money in the system goes to the BC Coalition of People with Disabilities to train advocates working in its offices.

I called the head Forensic Supervisor about getting a new worker but I was too intimidated to ask. I need an advocate to help me but there are no advocates in my city.

Chapter③

Recommendations for Systemic Improvements

In establishing a new position, the Advocate learned about the system and listened to people's experiences. The work was challenging, as the system was in the process of restructuring or developing, and the systemic issues underlying people's concerns were in some cases not obvious at first.

Through a process of consultation and qualitative analysis, people's concerns were aggregated into three broad themes for action:

- Foster dignity for persons living with a mental illness
- Create more uniform and responsive care
- Create stronger co-management of mental health reform

Recommendation 1: Foster dignity for persons living with a mental illness

Dignity is central because it is the foundation for self-respect, and without self-respect, recovery is very difficult, if not impossible. The Advocate suggests the Minister of Health can take five major actions to enhance the dignity of persons living with a mental illness. The first step requires addressing stigma and emotional literacy at the community level. More concrete action on poverty and the related housing issue for mentally ill people now living in the community must be forthcoming. Steps must be taken to minimize the effects of trauma in the process of care. Finally, dignity for complicated people living complicated lives can be maximized by ensuring access to an individual advocate who will bridge cultural differences and help resolve practical problems.

1.1 Address stigma and emotional literacy as a key feature in the Mental Health Plan

Informed by patient and family contacts, the Advocate worked to address stigma in public presentations and media commentary. Stigma exists at a societal level, where people with mental illness experience discrimination because of society's lack of understanding. It also exists at an organizational level, where, within health care, the needs of people with mental illness are placed at the end of the list.[8] The two kinds of stigma are reciprocal. Until the public stops blaming mentally ill people for their disability and signals it wants to have a health and social care system that provides support for people with health problems or disabilities equally, whether they are mental or physical, mental health needs will always be last in health care priorities.

The Advocate worked to make mental health more of a priority within the MoH. It is heartening to note those health authorities who have done this. Similarly, it is positive that the Ministry has recognized that those who work with the mentally ill at Riverview should be paid the same as those who work with physically ill people. (Currently, nurses at our provincial psychiatric specialty centre are paid on average $3.00/hour less than nurses in other health program areas.) These are important steps in the right direction.

In public meetings and open line radio shows, the Advocate was struck by the fact that many citizens lack basic emotional literacy. No one has taught them to distinguish between normal thoughts or feelings and those that indicate help is needed. Even after crisis contact with the system, consumers and families don't get basic information about the problem or how to support recovery. Calls to the Advocate's Office indicate front line providers do not routinely refer family members to publicly funded support agencies such as the BC Schizophrenia Society or to educational strategies that are proven to be effective for family and friends.[9]

Public funding for education about mental illness does not reflect the full spectrum of mental disorders. For example, there is no organized program to educate about anxiety disorders and support individuals to engage in self-care strategies with proven efficacy. People with depression and groups with newer diagnoses such as adults with Attention Deficit Disorder also want funding to support mutual aid activities.

Changing public attitudes is about information but it is also about people's values for the dignity and worth of each citizen no matter what his or her disability. Education that challenges values is more sophisticated than pamphlet pushing and almost always involves interaction or discovery learning.

The Ministry of Health funds provincial organizations to educate the public about mental illness. These educational activities could benefit from some strategic messaging to address stigma in a more powerful fashion. The excellent work begun by the CMHA in its Broadcasters of BC initiative needs to be continued. Further, the impact of these campaigns should be assessed over time by measuring changes in public attitudes.

Addressing stigma and improving educational strategies are not on the Mental Health Plan agenda.

Specific actions:

1.1.1 The MoH place combating stigma on the Mental Health Plan agenda and with the Health Authorities and advocacy groups develop a comprehensive strategy to address both societal and organizational aspects.

1.1.2 The MoH centralize funding for public information/referral lines.

1.1.3 The Health Authorities ensure that people who are leaving the hospital after a psychiatric admission are equipped with the necessary information and support to follow through with self care and formal mental health care.

1.1.4 The MoH review the allocation of provincial Education and Advocacy funds with a view towards allocating support for mutual aid to those with anxiety, depression and attention deficit disorder.

1.2 Address the poverty associated with serious mental illness

Being poor, and with that having minimal access to safe housing and nutritious food, makes recovery from a serious mental illness a constant uphill battle. To say that poverty robs people's dignity is to state the obvious, but well paid bureaucrats are often far removed from the reality of life in a single room occupancy hotel. The BC Benefits system has a commitment to improve its processes and an Inter-Ministerial Committee meets regularly to address Benefit-related issues, but significant actions don't seem to be forthcoming. Income Assistance issues for people with mental illness are not formally on the Mental Health Plan Implementation Steering Committee's agenda.

Certain policies require immediate attention. The Comforts Allowance of $82/month, which hasn't changed since 1994, has to be raised to enable those in mental health boarding homes and at Riverview to live a dignified life. The current practice of providing cheques on a monthly basis rather than every four weeks makes it hard for people to function in five-week months. The CPP initiative should be evaluated. There are certain policies of the BC Benefits system and the federal Canadian Pension Plan that need to be harmonized, given the significant numbers who now receive a combination of both benefits. The adequacy of the Dental Benefits needs to be addressed, given many mental health consumers have dental problems secondary to their medications.

People with mental illness who are hospitalized

Being poor, and with that having minimal access to safe housing and nutritious food, makes recovery from a serious mental illness a constant uphill battle. To say that poverty robs people's dignity is to state the obvious, but well paid bureaucrats are often far removed from the reality of life in a single room occupancy hotel.

or incarcerated on a nuisance charge should never lose their homes and their possessions because government regulations terminate the shelter allowance.

Specific actions:

1.2.1 The MSDES and the MoH address the policies and regulations of the BC Benefits program so as to meet the needs of the seriously mentally ill.

In 1999 there were approximately 60,000 people with serious and persistent mental illness and approximately 4905 housing spaces within the community mental system.

1.2.2 The MSDES raise the Comforts Allowance for persons in institutionalized care to a level that will support basic dignities of life in the year 2000.

1.2.3 The MSDES problem-solve the five-week month situation so income assistance payments come at regular intervals.

1.2.4 The Mental Health Plan Implementation Steering Committee, the Minister's Advisory Council on Mental Health (MAC on MH) and the MSDES evaluate the impact of the CPP initiative.

1.2.5 The mental health advocacy groups educate parents about the provision of discretionary trusts.

1.3 Address the housing issue

When care was provided in an institution, ill people received treatment, housing and sustenance. The downsizing of Riverview that began in the 1950s saw the uncoupling of this triad and with that the disappearance of 4200 beds from the system.

While no one would go back to the institutional model of care in the year 2000, British Columbia has still failed to provide housing for the mentally ill that is in any way coincident with the need. In 1999 there were approximately 60,000 people with serious and persistent mental illness and approximately 4905 housing spaces within the community mental health system.[10] The rest do the best they can. People on Disability Benefits with a shelter allowance of $325/month cannot participate in market housing. For example, in Vancouver in 1999 the average rent for a bachelor suite was $585/month.[11] By keeping the shelter allowance below market value, we are forcing mentally ill people to live in substandard and in most cases undignified and unsafe situations. Income Advocates wonder if increased support should go to the shelter allowance (the landlord) or support (personal use).

The needs in Vancouver are particularly acute. Since 1970, the affordable housing stock has been reduced from 13,400 single room occupancy units to 7,500 units in downtown Vancouver.[12] The current wait list for independent living units for mental health consumers in Vancouver/Richmond is 2600 people.[13] Vancouver/Richmond currently has 719 supported housing units and 92 supported housing units for mentally ill people with more intensive needs.[14]

While the 1998 Mental Health Plan targeted 2600 housing units and 1000 subsidized housing spaces as well as 244 residential care spaces for hard to house people, progress is slow. Since March 1998, 318 units of supportive housing and 170 units for forensic/hard to house individuals have been funded.

Solving the problem lies in three concurrent strategies: increasing the stock of both supportive and affordable housing, raising the shelter allowance to reflect market rates and developing a supportive strategy for the serious and persistently ill. By not providing housing to seriously ill people in the early phase of their illness, the system pushes them into the forensic and correctional systems where ultimately the solutions are much more expensive.

Specific actions:

1.3.1 The MoH, the MSDES and the Vancouver/Richmond Health Board come up with a housing strategy for the mentally ill that is coincident with the need.

1.3.2 The MSDES raise the shelter allowance for mentally ill people on Disability Benefits to reflect market values.

1.3.3 Progress towards implementing a housing strategy be reflected in regular reports to the Mental Health Plan Implementation Steering Committee.

1.4 Work to minimize the trauma associated with the care system

Trauma or violence in the care giving process is an unfortunate part of the mental health system. Based on contacts to the Advocate about traumatic experiences, it was clear no one had wanted to go where things had ended up. Trauma that is unrecognized and unacknowledged contributes to low self-esteem, self-medication with alcohol and other drugs and to a lack of willingness to participate in ongoing care.

A number of factors combine to put many people with mental illness in traumatic community or care situations. These factors include: the vulnerability to abuse that comes with the illness, the lack of early intervention following the person's first experience with mental illness, the lack of awareness of symptoms, the tendency towards self medication and addiction, and the tendency for those with concurrent disorders to receive no treatment. People who are ill and untreated get into trouble, potentially leading to victimization and criminal justice system involvement. People, particularly women who have been assaulted or abused in the past, often report the mental health system as reactivating that original trauma.

The BC Centre of Excellence for Women's Health is in the process of documenting women's experiences of trauma in the system. The BC Association of Specialized Victim Assistance and Counseling Programs has just completed training for workers in mental health gatekeeper skills. This network represents almost 200 agencies. A pilot participatory action research (PAR) project should be initiated to improve the situation. PAR uses research methods to create change.

The use of restraints and heavy doses of medication needs to be monitored, especially as it applies to people being transferred from small rural areas to regional hospitals by BC Ambulance.

Many consumers wanted to report their experiences of coercive treatment to the Advocate, but most administrators or professionals did not want to listen to the Advocate talk about these situations. A recent paper by the American National Council on Disabilities also notes this disquieting tendency for care providers to dismiss the reality of some patients' traumatic experiences.[15] However, it is curious that the traumatic experiences of staff working in Emergency settings appear to be on the change agenda.[16] It seems expedient that the users of the service and the service providers get together on this issue. Working together, it will get better.

Specific actions:

1.4.1 The MoH fund a pilot PAR project whose goal is to make the mental health emergency/crisis service less traumatic for consumers, providers and family members.

1.4.2 The MoH and staff from relevant professional bodies develop training in how to debrief clients who have experienced trauma.

1.4.3 The MoH approach BC Ambulance about changing its policies to be more supportive in transferring mental health patients in crisis.

1.4.4 The Mental Health Advocate monitor the use of restraints and seclusion practices in the province.

1.4.5 The Mental Health Advocate be given investigative powers to address allegations of abuse and neglect.

1.5 Work to develop a provincial mental health advocacy system

Access to advocacy allows a person with a psychiatric disability to preserve his or her dignity and get help in dealing with complicated situations. The calls to the Advocate's Office reflect people's troubles with daily life in the community and how hard it is for persons with a psychiatric disability to self advocate. Ensuring that persons with a mental illness and their families have access to advocacy for assistance with social, legal and therapeutic issues is a sign of a progressive mental health system.

Mental Health Advocacy offices are very common institutions around the world. They exist in 56 US states and territories, Australia and New Zealand, as well as the provinces of Alberta, Ontario and New Brunswick. As an office independent of the service system, for the most

Trauma that is unrecognized and unacknowledged contributes to low self-esteem, self-medication with alcohol and other drugs and to a lack of willingness to participate in ongoing care.

part, they exist to protect, defend and make things better for mental health consumers."

For systemic advocacy to be credible, it must be informed by local advocates and people with the disability. The current BC system of advocates is very patchwork and needs pulling together.

The challenge is to build an advocacy system compatible with a regional health care system. For systemic advocacy to be credible, it must be informed by local advocates and people with the disability. The current BC system of advocates is very patchwork and needs pulling together. For example, there are currently two Ministry of Health-funded mental health information/referral services: the Advocate's Office and the BC Mental Health Information Line contracted to the Canadian Mental Health Association—BC Division.

The Ministry has two choices. It could put all of the advocates, systemic and individual, under one mandate as is done in other jurisdictions, or it could develop a formal Advocacy Network. Individual Advocates in the Health Authorities, Advocates at Riverview Hospital, the Income Advocates with the Mental Health Empowerment Advocates Program and the Legal Advocates with the Community Legal Assistance Society need some way to systematically report to the Provincial Mental Health Advocate. Input from the provincial mental health advocacy organizations also needs to be systematized. The current system features much hard work and little systematic reporting about whom is served for what purpose.

There is a tendency to think that doctors, nurses and social workers can act as patient advocates.

There is a tendency to think that doctors, nurses and social workers can act as patient advocates. While they can and do, the calls to the Advocate's Office in 1999 indicate that often independent advocacy is required to mediate a solution. The advocacy services in other jurisdictions work as a part of a continuum of existing local and provincial complaints processes.

For mental health consumers in BC, access to advocacy is not universal. While a system for independent individual advocacy in the Health Authorities is crucial, independent advocacy for individuals engaged in the forensic system seems particularly important.

Further, because there is no explicit Health Authority policy legitimizing advocates, there are no standards for practice or training for mental health advocates.

Access to advocacy in dealing with concerns related to private physicians needs to be addressed. When an individual complains about ineffective or inappropriate care to the College of Physicians and Surgeons of BC, a copy of the complainant's letter is sent to the named physician for a reply. People called the Advocate to say they felt they were being poorly treated by the physician in the first place and further trivialized and humiliated by a complaints process that takes a long time to complete and seems to favour the professional.

Specific actions:

1.5.1 Health authorities, the MoH and the Mental Health Advocate work to develop a standard for independent individual advocacy in each Health Authority.

1.5.2 Health authorities and the MoH work to make existing complaints management processes more independent and visible to mental health consumers and their families.

1.5.3 The Forensic Psychiatric Commission work to provide independent advocacy to patients in this system.

1.5.4 The Provincial Advocate work with health authorities, the MoH, the Advocacy Community and community colleges around the province to develop a training program for advocates.

1.5.5 The MoH approach the College of Physicians and Surgeons to create a complaints process that is appropriate for psychiatric patients.

1.5.6 The MoH and the Mental Health Advocate work with the various provincial advocacy groups and advocacy programs to create an Advocacy Network with reporting mechanisms so that systemic advocacy can be informed by the experiences of individual advocacy.

Recommendation 2: Create more uniform and responsive care

The recommendations around care begin with outlining the necessity for provincial standards for mental health care in a regionalized system. Implicit in standards for care are standards for patient rights in the system.

There is also a need to continue with current provincial initiatives related to mental health information systems, early intervention, emergency services, mentally disordered offenders and the needs of the seriously or persistently ill person. Part of making the system more sensitive to the needs of the mentally ill is strengthening the role of consumers as providers in the system. The Advocate suggests that in order to create more uniform and responsive care the Minister can take four actions:

2.1 Set standards for care and patient rights

In the present health care system, the regions are responsible for delivering care, but the Ministry has a responsibility to establish standards so that care will be uniform across the province. Currently it is not, with different regions having different service complements. For example, access to after hours emergency mental health workers and crisis lines to avert hospitalization are not universally available. While the MoH has promoted "Best Practices" in seven key areas, service standards would represent yet another level of commitment to doing the right thing.

Australia has developed mental health care standards that could be referenced.[18] Interestingly, Patient Rights is the first standard of care in the Australian example. Riverview Hospital has developed a Bill of Patient Rights, but it focuses largely on the structure and issues that arise in a tertiary facility. A provincial standard that is more community-focused is required for BC. With clearly laid out standards, the Advocate's job becomes easier, as there is a statement of commitment by the system to hold up when a client contacts the Advocate with a concern about care.

Consumer Advocates are especially concerned that patients involuntarily confined under the Mental Health Act are not being given basic rights advice.[19] In site visits to rural communities, the Advocate observed that often when this is the case it is because the first point of contact for a person in crisis is often a general duty nurse with no training in psychiatric issues. It is understandable that staff who are not adequately trained are not comfortable explaining rights, but from the patient's perspective this is a crucial step in a respectful care encounter.

In service audits, site visits and consumer meetings, the Advocate learned that independent rights advice to involuntary patients is variously applied across the province and the Ministry appears to have adopted a model where service providers are to fulfill this function. Some communities have had no Mental Health Review Panel hearings in the past year, indicating that no psychiatric patients were supported in reviewing their involuntary status. The November 1999 revisions to the Mental Health Act require that patients sign a form indicating they have been advised of their rights, but research in other jurisdictions questions if information provided this way is actually understood.[20] The effectiveness of this policy change and how it might relate to the provision of formal individual advocacy in the regions must be addressed. The review must avoid the tendency to look at legal rights in isolation from social and therapeutic rights; these various aspects of rights form part of a continuum that signifies dignified care. In New Brunswick, all involuntary patients are advised of their rights by advocates associated with the provincial Mental Health Advocate's Office. These advocates address legal, social and therapeutic rights of psychiatric patients.

Specific actions:

2.1.1 The MoH and the health authorities work together to develop standards for mental health care, including standards for patient's rights.

2.1.2 The Mental Health Advocate in collaboration with the new MAC on MH and Regional Mental Health Advisory Councils develop a Bill of Patient Rights that could serve as a standard for Advocates assisting people with mental illness.

Part of making the system more sensitive to the needs of the mentally ill is strengthening the role of consumers as providers in the system.

2.1.3 The Mental Health Advocate review the current situation regarding rights advice to mental health patients and how it fits into regional plans for independent advocacy.

2.2 Access to community care must be improved for the sickest people

Studies carried out in Canada report that about 50% of people with schizophrenia have a substance misuse problem. For individuals with a diagnosis of depression, the proportion is even higher at 60%.

Among people with serious mental illness who have had a first encounter with the system, it takes on average seven years to get a diagnosis.[21] Of those with a diagnosis, only an estimated one in three people is in the treatment system.[22] Estimates of the percentage of persons with serious psychiatric illness that have either lost contact with, or have never been in contact with specialized mental health services may be as high as 45%. In a review of 1997-98 mental health sector service utilization by people diagnosed with either schizophrenia or bipolar disorder, less than 12,000 of an estimated 60,000 were identified as registered within the community mental health system.[23]

Seriously ill people who live in rural areas are disadvantaged because of lack of access to specialist care. The current $1 million TelePsychiatry initiative is an exciting direction.

Seriously ill people aren't easy to serve. They often fall out of the mental health system into the forensic or correctional systems. In 1998-99, FPI assessed 227 individuals and treated a further 22, while the 6 community clinics assessed 738 people and treated 2826.[24] When people are undiagnosed or the forensic system is full, people waiting for assessments end up in local correctional facilities. People who are charged, in jail and mentally ill tend to receive minimal or no treatment. BC Corrections Branch is making a worthy attempt to recognize this. The Director of Mental Health for Corrections has just completed screening inmates in five out of six provincial correctional facilities and found 32% of inmates with signs of mental disorders.[25] A plan for providing improved treatment to inmates is in preparation. This will present challenges to FPI, as currently doctors there are frequently unable to offer treatment to someone with a mental illness in jail, as they are mandated to do by the Forensic Psychiatric Act.

When people are discharged from jail or FPI, the pressure by the Court system is to ensure that they are cared for in the most normalizing situation. The burden is on the forensic workers to demonstrate that the person will be a risk to the community.[26] Increasingly, community mental health staff are asked to provide care for people coming out of the forensic and correctional systems. Reports to the Office indicate staff are not always prepared for this and some people are turned away. The community mental health, forensic and correctional systems form part of the Mental Health system and staff need to be comfortable working with people with severe and persistent illness. The existence of considerable overlap between the two populations is demonstrated by a study that found that 53% of a sample of patients at Riverview have pre-existing criminal charges.[27]

Without care, people often self-medicate with alcohol or drugs. Studies carried out in Canada report that about 50% of people with schizophrenia have a substance misuse problem. For individuals with a diagnosis of depression, the proportion is even higher at 60%.[28] The fact that a significant number of people with mental illness also have addictions should not be cause to reject them from service. The recent announcement of a pilot project on concurrent disorders is a welcome step in the right direction. The recent creation of 170 supported housing spaces for people coming out of the forensic system is another welcome addition, but likely these spaces will be filled very quickly.

Currently, initiatives for mentally ill people in the forensic and correctional systems are not communicated to or coordinated by the Mental Health Plan Implementation Steering Committee.

Specific Actions:

2.2.1 The MoH monitor the participation rate of seriously ill people in the regional mental health systems, the forensic system and the correctional system.

2.2.2 The Forensic Psychiatric Commission develop alternate strategies to fulfill its mandate to treat mentally ill people in jail.

2.2.3 The Regional Health Authorities support community mental health staff to develop creative ways to work with those

hardest to reach that are particular to regional needs.

2.2.4 The MoH and the health authorities continue with proposed pilot programs to treat people with mental illness and addictions.

2.2.5 The MoH and the health authorities continue with and evaluate the impact of the current TelePsychiatry initiative.

2.3 Continue with a strong focus on early intervention

Most people experience their first episode of mental illness between 17 and 25 years of age.[29] Some experience the illness much younger. People who contacted the Advocate raised serious concerns about the availability of services for children and youth. As much as the system needs to focus on the serious and persistently ill, it also needs to intervene early. Because people come to care too late, they can experience unnecessary suffering and grow resistant to treatment. The work begun by the MoH, health authorities and the MCF on the BC Early Intervention Strategy is important.

The community mental health service system is divided into a children's and an adult service which begins at age 19, with the segments managed by two different Ministries. This leads to problems of continuity of care, especially when all ages receive crisis care at a hospital in the health care system. Reports by parents and professionals indicate concerns about resources for recovery-oriented services for children and youth.

But early intervention should not just focus on child and youth services. Early intervention should mean getting the person the right help the first time. Unfortunately, because of lack of awareness of mental illness, many people's first encounter with the system is in a crisis. This is why a good crisis response system is so basic to the mental health system. It was shocking to hear people say that their experiences in emergency care were so traumatic and humiliating they would prefer to stay out of the system, or be taken to jail rather than a psychiatric facility.

Specific actions:

2.3.1 The system continue to foster an Early Intervention approach. The work that has begun with one time funding continue with annualized funds.

2.3.2 The government make child and youth mental health a part of the health care system.

2.3.3 The MoH continue the current initiatives to improve the quality of emergency mental health care in rural areas.

2.3.4 The MoH develop and provide the Provincial Advocate's Office and health authorities with practical packages of information and support for individuals and families having their first mental health system experience.

Early intervention should mean getting the person the right help the first time.

2.4 Access to peer support services will improve access to community care

Considerable effort is made in BC to involve mental health consumers as providers, planners and systems evaluators. Progressive service systems employ a variety of strategies for consumer support alternatives, including self help and peer support, consumer operated programs such as clubhouses, and consumer employment in community mental health or in non profit community organizations. More direct programming supports the creation of consumer-run businesses.[30] Central Vancouver Island Health Region has supported the development of a program that trains peers to act as advocates in hospital and community rehabilitation settings.

While consumer involvement has been associated with reduced hospitalization, reduced use of other services, increased knowledge, information and coping skills as well as increased self-esteem and stronger social networks for the consumer provider, involvement can bring improved health to the recipient of service as well.[31] Research data shows that use of peer providers results in increased program engagement, reduced psychiatric symptomatology, increased self-esteem and improved social networks.[32] Other research from consumer development initiatives reports similar success with

Most people experience their first episode of mental illness between 17 and 25 years of age.

health outcomes for consumers engaged in consumer-run businesses.[33] The Vancouver/Richmond Health Board has funded several small consumer-run businesses, but the initiatives are not widespread.

The Advocate observed that many health authorities are engaging in peer programming. Most of the programs are funded under the Consumer Family Initiative funds. However, some programs could benefit from evidence-based program planning principles as well as funding to support evaluation of the innovation. The Advocate also observed that peers could potentially be most useful in urban core, rural and Aboriginal communities. The current Women's Mental Health initiative has funded several peer support strategies.

People in the field, consumers and family members are confused about what the Mental Health Plan means.

Specific actions:

2.4.1 The MoH and health authorities develop a policy paper to guide the use of peers as providers in the mental health system.

2.4.2 The MoH fund projects to support consumer-run businesses.

Recommendation 3: Create better management strategies to support implementation of the Mental Health Plan

The 1998 Mental Health Plan is a broad vision statement with many different commitments for reform. Currently, there is no public process that tracks accomplishment of objectives. The Advocate observed that this is complicated by health authorities' own plans, but if service standards were in place, tracking might be more matter of fact. The fact that many of the targets require systematic support over a number of years is another complicating factor.

The 1998 Mental Health Plan did not address a management strategy for implementing this reform process. The Advocate recommends that the Minister take four steps to strengthen the implementation of the Mental Health Plan.

3.1 The Mental Health Plan has to be measurable

People in the field, consumers and family members are confused about what the Mental Health Plan means. The Advocate, and for that matter community members, cannot track progress if the system managers do not present their targets and accomplishments in a measurable strategic plan. The Ministry has developed a Performance Monitoring Framework, but it is not tied to deliverables of the Mental Health Plan. Work must continue to develop a concrete Mental Health Plan with measurable outcomes.

Measurement of program success is even more difficult without the benefit of computerized patient databases and quality improvement surveys of client satisfaction with the system. The BC Mental Health Information Management Project is an important systems building block that has just begun. This project has paid particular attention to strategies to protect patient confidentiality and privacy. This work must continue.

Work in the area of patient feedback has also just begun and must continue and focus on assessing performance of the local service system in specific settings.

Specific actions:

3.1.1 The MoH develop a Phase 2 Mental Health Plan based on the broad goals of the1998 Mental Health Plan and update this plan on an annual basis in a collaborative process involving the Health Authorities, community agencies, consumers, families and physicians.

3.1.2 The MoH revise the Performance Monitoring Framework to measure indicators for success in the Strategic Plan for Mental Health.

3.1.3 The MoH provide ongoing funding to the BC Mental Health Information Management Project.

3.1.4 The Mental Health Advocate work to ensure the protection of patient confidentiality associated with the BC Mental Health Information Management Project.

3.1.5 The MoH continue to support Consumer and Family Satisfaction Surveys that are specific to regional settings.

3.2 Leadership for mental health reform must come from more than the Health sector

There is general disagreement about the most important problems to solve. While it is more logical for the MoH and health authorities to focus on service system issues, people will not recover from mental illness without a larger vision of community support. As articulated in the Canadian Mental Health Association's Framework for Support,[34] the areas of poverty, housing, criminal justice system liaison and community integration are essential to any progressive mental health strategy. The Mental Health Plan Implementation Committee currently lacks any senior level participation from other sectors.

Specific actions:

3.2.1 The management strategy for the Mental Health Plan include standing updates by senior officials of the MSDES, the MCF, the Ministry of the Attorney General and the Ministry of Education.

3.2.2 The Mental Health Advocate meet twice a year with the Ministers named above to report on progress with the Mental Health Plan.

3.3 Continue to involve consumers and family members in the management of change

The 1998 Mental Health Plan lists continued consumer and family involvement in mental health reform as an ongoing challenge. A new Minister's Advisory Council on Mental Health has just been announced. The Advocate looks forward to working with it to provide another user focused voice to provincial policy initiatives.

The current Mental Health Plan Implementation Steering Committee lacks any input from Consumer representatives. This must change.

The Advocate has reviewed the Regional Mental Health Advisory Committees and in a published report made recommendations for strengthening these groups.[35] In subsequent reports, the Advocate will once again review the status of participation and look towards more concrete accomplishments from these groups.

Specific actions:

3.3.1 The Minister of Health and health authorities respond to the Advocate's suggestions to strengthen consumer and family input at the regional level.

3.3.2 Consumer representatives be appointed to the Mental Health Plan Implementation Steering Committee.

3.4 Develop the workforce

Mental Health reform in other jurisdictions features a workforce development strategy. For many years, mental health has not been considered the place to work in health care. People were systematically paid less. The work was custodial and not portrayed as glamorous. Most recently, those in the field have gained pay equalization, but with increasing volumes of patients and minimal increases in resources, the field is characterized by burnout and stress. This situation is particularly acute in rural areas. It isn't good for consumers, their families or the workers.

The New Zealand Workforce Development Strategy is exciting.[36] Not only are workers trained in basic skills such as emergency care or cognitive behavioral approaches but also in specialty skills such as working with people with dual diagnosis forensic histories. There are also innovative programs to train Aboriginal mental health workers and consumers to be front line providers. The MoH this year announced significant funding to the MHECCU at the University of BC. More recently, funding was announced to support training for general practitioners in psychiatric medicine under a shared care model. Currently, there is no overview on workforce development available.

Specific actions:

3.4.1 The MoH put workforce development as a standing item in its Mental Health Plan and it be monitored by the Mental Health Implementation Steering Committee.

Chapter④

Conclusions

This report details the experiences of the first year of operation of the Office of the Mental Health Advocate of BC. It was exciting to meet so many people and visit communities and look at service systems. It was also a tough year. People have many difficulties with the mental health system. There is limited access to formal Individual Advocates to help people who end up in complicated situations. Faced with an unstable chronic illness, people also have trouble living well in the community. They have difficulty earning a living or accessing disability benefits. Housing is in short supply. Their illness, especially if untreated and acute, can get them into trouble. People report discrimination and experience stigma.

Twenty per cent of the community will have a diagnosis of a mental illness in any one year. Fewer than one in three of these people are in the system. The unmet need is real and the resources finite. There is limited access to advocates who could help broker solutions to unique situations. New systems are developing at the regional level. Progress towards a community mental health system varies from region to region across the province. Riverview and the Forensic system have agreed to chart separate futures.

There is much hope that things will be better, but change takes time. This report points to some specific actions that will hurry change along... from the perspective of people living with mental illness.

The report suggests the concerns of the people living with mental illness be addressed in a Phase 2 Mental Health Plan that features a more collaborative management process than currently exists. The tension between health authorities' need for autonomy, consumers' and family members' need to be involved in a meaningful way and the Ministry of Health's need to maintain a provincial system of care must be resolved.

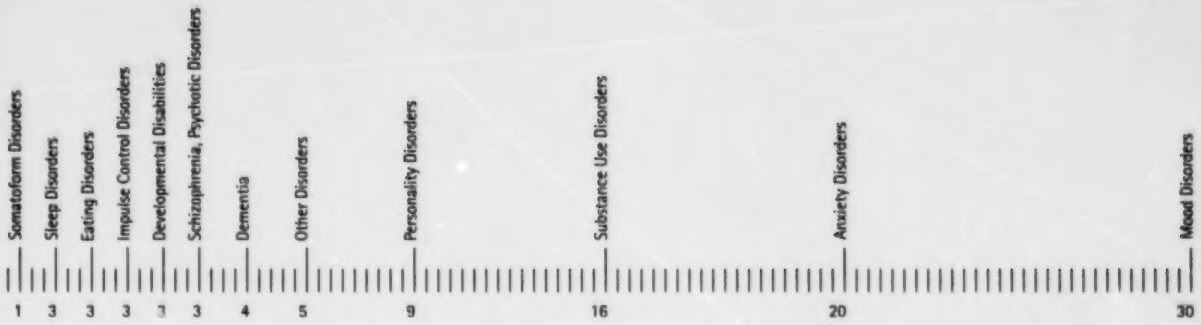
Currently in most systems, anxiety, depression and substance use disorders account for three times as many patients and ambulatory consultations as do schizophrenia, bipolar disorder and severe cognitive impairment

This collaborative process must exist in a certain amount of dynamic tension which appreciates four paradoxes that resonate in the mental health policy-making environment. These paradoxes are:

People are chronically ill; some people recover; mental illnesses are not all the same

The past year has seen considerable policy debate about the necessity to focus on the needs of the seriously and persistently mentally ill. These people represent 3–4% of the population, a small portion of the 20% of the population who might suffer from a mental illness in any one year. The Ministry has written a policy paper advocating the health authorities focus on the seriously ill population by limiting scarce resources to this end.[37] Allocating resources on the basis of the burden of disease would result in more effort being made to address schizophrenia and severe bipolar illness. It would leave people with depression, anxiety disorders and mild bipolar illness to function on their own, perhaps with the help of a private physician. People with these conditions want access to newer group and behavioural/supportive counseling. This is a significant women's mental health issue, as women comprise 60% of those with anxiety or depression.

But another way of approaching the problem would be to offer services according to the availability of cost effective treatments. Currently in most systems, anxiety, depression and substance use disorders account for three times as many patients and ambulatory consultations as schizophrenia, bipolar disorder and severe cognitive impairment.[38] While the former diseases are more common, staff in mental health centres and community hospitals may not have received training in how to treat them. Because effective treatment strategies exist for these most common disorders, there is good reason to



One in five people will experience a mental illness next year. If you put 100 people with a mental illness into one room, the distribution of diagnoses would look like this.[40]

question a system that devotes the majority of its resources to the needs of people with psychoses.

Given the frequency of the problem and the person/days lost to the community, it would seem prudent to have a strategy for both thought disorders and the more common mood disorders. If clinicians have access to effective drug and non-drug treatments for 90% of individuals with mental illness and most patients will respond to treatment within 30 days,[39] why wouldn't a system develop a response for these more common health problems? Those who are advocates for mental health understand this decision has resource allocation, planning and training implications.

The Advocate suggests that conducting the target group discussion as an either/or enterprise tailors the actions to the available resources but has huge social costs that cannot be ignored. In any case, one can question whether the issue is more resources or better use of the almost $107 million dollars/year that are already spent on physician services for mental health care.[41] The real barrier towards a comprehensive plan that addresses the burden of illness and the availability of cost-effective treatment for the most common conditions is collaboration. Action would require the MoH, health authorities and Physicians developing a collaborative relationship and a population health strategy to educate and promote system engagement.

Leadership must be simultaneously top down and bottom up

The health system has decentralized services and created regional and local governance systems. The Advocate noted considerable tension between the health authorities and the MoH about who is leading this new system. The answer lies in respecting regional and local autonomy, fostering local creativity and monitoring and evaluating the progress towards provincial standards of care.

The Mental Health Evaluation and Community Consultation Unit at UBC has the potential to offer useful information regarding system performance. The BC Mental Health Information Management Project has the potential to realize a provincial information system to help foster continuity of care. Actions in these areas need to be supported over time and fed into the Mental Health Plan management process.

Evaluation of the Mental Health Plan implementation process can help. As with any new endeavor, the early stage evaluation strategies should focus on improving process; later stages can focus on outcome once the programs are implemented. Process evaluation asks: "What's working? What's not? And what can we do to make it work better?" It reinforces successes and identifies challenges in a non-blaming manner.

In order to coordinate the activities of the different sectors and regions, the Ministry should give serious thought to deploying a Secretariat to manage the implementation of the Mental Health Plan. Other jurisdictions, such as New Zealand and New Brunswick, have successfully used a time-limited Mental Health Commission to guide the Mental Health Plan implementation process. Whatever is done, it needs to feature sensitivity to collaborative process, because that is what an integrated, co-ordinated and non-discriminatory mental health system is all about.

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Health services are expensive. They do very little to address the conditions of everyday living experienced by a person with a mental illness.

There is more to health than health care; our funding must reflect this

Health services are expensive. They do very little to address the conditions of everyday living experienced by a person with a mental illness. Policy makers have to balance the amount of money spent on programs with money invested in housing, income security and community meals programs for people with psychiatric disabilities. This tension between meeting the needs of the chronically ill by providing crisis care (more beds) or chronic care (more housing and community support) is perpetually evident in the discourse around health care. A recent study on housing for the Vancouver/Richmond Health Board found that people with psychiatric disabilities will require 70 days longer hospitalization if they don't have adequate housing.[42] The job becomes even more difficult when solutions involve action from other Ministries.

There is currently public debate about the seeming drift towards two-tiered health care. Some people have made the observation that, in mental health care, a two-tiered system already exists. Those with money can go to private counselors or explore alternative treatment modalities such as bodywork or non-drug nutritional approaches. Those without money have to rely on the public system, which offers a narrow range of services and only cares for the very sickest.

Care must be respectful and empowering, and sometimes coercion is required

Some people who are seriously ill may require restrictions and more intensive case management. The fact that 23% of psychiatric hospitalizations are involuntary reminds us that there are times when people in psychiatric crises need to be in safe places.[43] The new Mental Health Act legislation supporting extended leave suggests there is a need to maintain some people in a more supervised environment. Many people question whether there are sufficient resources to implement these revisions. The danger of focusing on coercion without holding on to the empowerment dynamic is that resources can easily be eaten up by services for the very few who require control.

But another way of planning services is to recognize that almost 75% of psychiatric hospitalizations are voluntary and people need to be supported to engage in their own recovery. Examples from innovative, recovery-oriented initiatives such as Providence Farm, located outside Duncan, and A-Way Express in Toronto, suggest there is real potential for people who are very ill to recover and contribute to society. A wise system, it would seem, would balance expenditures on restricted care for the very ill with recovery-oriented community ventures.

Balancing these paradoxes

Balancing these paradoxes is an art that can be supported with an effective system for mental health advocacy at the provincial and regional levels. The variety of concerns raised to the Advocate's Office in the first year underlines the importance of the Advocate's potential role in listening and in balancing the inevitable tensions.

In closing

This report presents ideas for systemic improvement generated from contacts with people living with a mental illness and their advocates and care providers. Chapter 3 defines three broad directions for system improvements as well as specific actions that could be taken to accomplish this. The Advocate asks the Ministry to develop a Phase 2 Mental Health Plan and create a Mental Health Commission to monitor its implementation. Finally, as change is a process that takes place through dialogue, the Advocate recommends the report be discussed by the Minister of Health, the Ministry of Health executive, the MAC on MH, the Regional Directors of Mental Health, health authorities and consumers, families and community organizations. As a number of recommendations would require action by other Ministries, the Advocate also asks the Ministers of Social Development & Economic Security and Children and Families and the Attorney General to review this report and strengthen the collaborative process with the Mental Health Plan.

Epilogue

As I was finishing this report, I took a break from my computer screen. I turned on my television to watch the popular series, "ER." To my horror, a man with schizophrenia in the process of his first hospitalization had stabbed the show's hero, Dr. Carter, as well as Lisa, another young doctor working in the Emergency Room. The thrust of the script was that the mentally ill man had victimized the show's heroes. Dr. Lisa died in the course of the episode, while Dr. Carter lay critically injured, with news of his recovery to wait until the next week.

The reason this portrayal of a mentally ill man in Emergency upset me was that in real life, the exact opposite happened in December 1999. At the Langley Memorial Hospital Emergency Room a police officer shot and killed a mentally ill man who was in the process of accessing care.

Unfortunately, having spent the last 18 months listening to the needs of the mentally ill and proposing change to the health and social care system, action to address mental illness in this province is framed by the kind of social perspective portrayed in the ER show. The mentally ill are still blamed for their symptoms and discriminated against in community life as well as in the setting of health care priorities.

This is changing because it must. It is time to shed historical perspectives on the mentally ill. According to latest estimates from the World Health Organization's Global Burden of Disease project, mental illness now exceeds HIV or cancer in terms of numbers affected.[44] Estimates vary, but at this time, mental health care in BC represents only about 7% of the total health care budget.[45] As is obvious in this report, the province is moving in the right direction, but significantly more effort is required. Because recovery is so possible and mental illness so common and disabling, it would be economic folly for the Provincial Government not to proceed with the implementation of the Mental Health Plan in a more assertive fashion.

Notes

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